The efficacy of using Appropriate Paper-based Technology postural support devices in Kenyan children with Cerebral Palsy.

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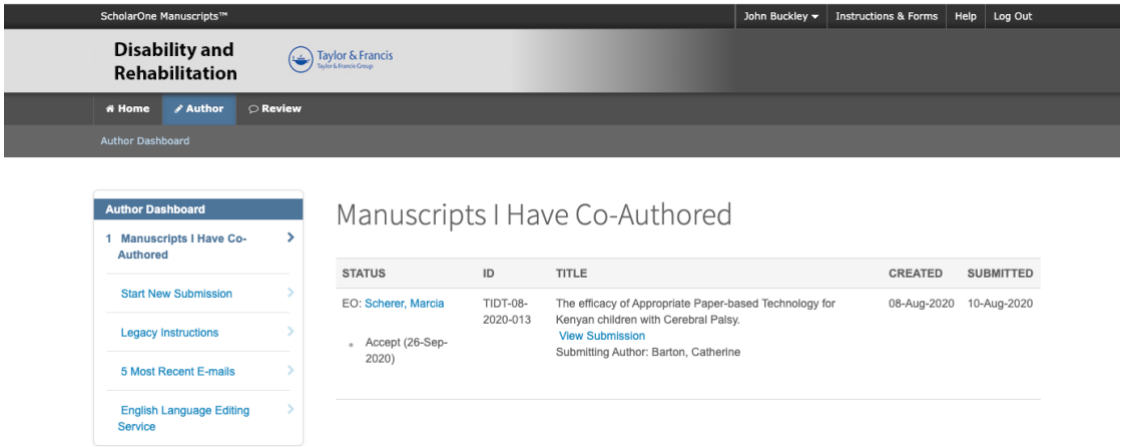

The efficacy of using Appropriate Paper-based Technology in Kenyan children with Cerebral Palsy.

Abstract

Purpose: Appropriate paper-based technology (APT) is used in providing postural support for children with cerebral palsy (CP) in poorly health-resourced countries. This pilot study aimed to evaluate the impact of APT on the children's and families' lives.

Materials and methods: A convenience sample of children with CP and their families participated. Inclusion was based on the Gross Motor Function Classification System levels IV and V. APT seating or standing frames were provided for six months. A mixed methods impact of APT on the children and families included the Family Impact Assistive Technology Scale for Adaptive Seating (FIATS-AS); the Child Engagement in Daily Life (CEDL) questionnaire; and a qualitative assessment from diary/log and semi-structured interviews.

Results: Ten children (median 3 yrs, range 9 mnth - 7 yrs). Baseline to follow-up median (IQR) FIATS-AS were: 22.7 (9.3) and 30.3 (10.2), respectively ($p = 0.002$). Similarly mean (SD) CEDL scores for "frequency" changed from 30.5 (units of frequency?)(13.2) to 42.08 (5.96) ($p=0.021$) and children's enjoyment from 2.23 (0.93) to 2.91 (0.79) ($p = 0.019$). CEDL for self-care was not useful; seven families scored zero at both baseline and 6 mth. Qualitative interviews revealed three key findings where APT improved functional ability, involvement/interaction in daily-life situations, and a reduced family burden of care.

Conclusion: APT used in Kenyan children with non-ambulant CP had a meaningful positive effect on both the children's and their families' lives.

Keywords: Cerebral palsy; resource limited country; paper technology; adaptive seating; standing frames; assistive devices

Implications for rehabilitation

- Assistive devices are often unobtainable for children with cerebral palsy (CP) in low-income countries.

- APT is a low cost and local solution to make seating and standing devices for disabled children in Kenya.

- The regular use of a postural support device enhanced the children's motor skills, ability to function and participate in everyday activities, reduced the burden of care for the families and promoted the children's social interaction.

- The postural support devices were both valued and highly utilised by the children and families in this study.

Introduction

Cerebral palsy (CP) is the most common neurological condition and cause of physical disability in children worldwide, affecting ~1 in 500 live births with lasting impact [1,2]. In Africa, CP is thought to be more prevalent than in most other countries, [3,4]. In 2019, Kenya had 1.75 million live births meaning each year ~3,750 new children and families will be living with the challenges of CP [5,1]. Approximately 40% of children with CP suffer from a severe non-ambulant form and are unable to sustain a sitting or standing posture [6] and will require therapy support services throughout life [7].

Postural support devices, including seating and standing frames are used as assistive technology therapy for children with CP [8] (Figures 1 and 2).

[Figure 1, Figure 2. Near here]

These devices known as "assistive technologies" aim to overcome children's challenges with motor control due to abnormal muscle tone, co-contraction, loss of selective movement and muscle weakness [7]. For the children and their families it means a more socially interactive, comfortable and functional seated or standing positions, and helps to prevent prolonged periods of lying in one position [8]. Furthermore, improved postural control, leads to enhanced function and prevention of deformities and fractures that could lead to further disability [8,11-18]. Specifically, the nature of such motor disorders include hip dysplasia, fractures, muscle contractures and scoliosis [20]. Without postural support devices these children spend long periods in limited positions and asymmetrical postures which causes body shape distortion and can result in painful musculoskeletal deformities and inadequate participation in normal daily life. These factors lead to significant social isolation from both their families and community. The

is therefore to find ways to provide affordable seating and standing frames to promote better growth and development physically and socially [21-23].

In countries with well-resourced health care services like the UK, advanced assistive technologies are provided as part of routine medical and therapy care [7,9,10]. However, the World Health Organisation (WHO) has reported that assistive technology in low-middle income countries (LMICs) is only available for 5-15% of those requiring them [19]. These data concur with our team's experiences of working with children with CP in Kenya, where assistive devices are rarely provided. Efforts to resolve this challenge has included charitable donations for health technologies but often the donated equipment is unusable for a variety of reasons including: it is not adjustable to the child's ability, size or environment, or it is broken and there is no one to repair or to adjust it [24-26]. Wooden seating and standing devices have been used in some settings but are expensive to produce locally, are difficult to adapt to the growing child and unaffordable for many families [27-30]. A sustainable low-cost solution to this problem in Africa has been the use of appropriate paper-based technology (APT) [26,31]. These seated and standing frames can be made inexpensively and locally and adapted to the individual needs of the child

The design and construction process of APT assistive devices has been refined by the charity Cerebral Palsy Africa (www.cerebralpalsyafrica.eu), using recycled cardboard, newspaper and flour-based glue. The production of APT however requires training and the labour can be intensive. Fortunately there are training courses in constructing APT for volunteers from the children's own community [31]. An APT manual of design, construction and training has now been published based on courses run in Africa [26].

Currently, only anecdotal reports on the physical, psychological and social efficacy of APT exists, which comes from caregivers and those making APT . The opportunity to collect and report more objective evidence on APT efficacy has arisen from a tri-partnership between Cerebral Palsy Africa , Powys Health-care (Wales, UK) and a Kenyan non-government organisation, the St Martin Catholic Social Apostolate (CSA) based in in Nyahururu, Laikipia County. St Martin CSA provides centre-based and outreach services for disabled children and adults, where they have gained considerable experience, since 2012, in the construction and use of APT. In a three year period, St Martin CSA have produced over one hundred APTs for the Nyahururu community. The primary aim of this study was therefore to evaluate the efficacy of APT on the quality of and participation in life of children with severe CP in Kenya. A secondary aim was to evaluate the acceptability of APT by both the children with CP and their families.

Materials and methods

The research was conducted in partnership with St Martins CSA, Nyahururu, Laikipia County, Kenya. Two staff members from St Martins CSA disability programme agreed to become research assistants for this project and completed an advanced APT course in the UK. This was followed by a refresher APT course at the CSA Centre in March 2015. Ethical approval was obtained from the Scientific and Research Ethics Committee at Aga Khan University, Kenya, including a permit from the Laikipia county.

Participant Recruitment

A convenience sample of 12 children with CP were identified through St Martins CSA from families living in the Nyahururu community. At the time of invitation to volunteer,

the families were given an illustrated participant information leaflet written in the local languages of Swahili or Kikuyu. A local language interpreter helped answer any further questions about the research.

Eligibility included children meeting the following criteria:

- Aged 1-6 years with a diagnosis of bilateral CP,
- Non-ambulant severe motor dysfunction classified at levels IV and V of the *Gross Motor Function Classification System* (GMFCS),
- No previous us of a postural support device,
- Able to tolerate and cooperate with detailed assessments,
- For children attending school, they were supported by a caregiver able to transport the APT device to and from school.

There was a bias to recruiting preschool aged children because current models of neuroscience promote the importance of early intervention to foster brain reorganisation and neural plasticity, which is thought to be greatest at this time [33].

Ineligible Families included children with severe uncontrolled epilepsy, due to the possibility of harm resulting from a seizure whilst in the APT

The Gross Motor Function Classification System (GMFCS),

The GMFCS was used for both sample selection and sample description. It is used internationally as a reliable and validated measure [34,35]. It is a five-level classification that includes a child's current gross motor abilities, limitations in gross motor function and the need for assistive technology and wheeled mobility [36].

Children at GMFCS level IV can sit on a chair but need adaptive seating for trunk control and to maximise hand function. They move in and out of chair sitting with assistance from an adult or a stable surface to pull up on with their arms. Children may at best walk short distances with a walker and supervision but have difficulty turning around and maintaining balance on uneven surfaces. Assisted devices are needed to improve head alignment, seating and standing [37].

Children at GMFCS level V have physical impairments that restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures, and where all areas of motor function are limited. For both GMFCS IV and V, children require the need for assisted transport. .

Study Design

A mixed-methods design using both quantitative and qualitative data was used to strengthen the validity of the research findings through triangulation, with the overall addressed aim of giving a greater understanding of any physical and social outcomes, including the acceptability of APT. Quantitative results were assessed by a repeated measures design using parent-reported questionnaires. Where possible, inferential statistics were used to verify any changes in the children's function, participation in daily life activities and wellbeing after the six months of using APT.

The qualitative analysis applied a contextual methodology to explore the experiences and perspectives of the primary caregivers of the children. A deductive approach was used in the descriptive phenomenological tradition of seeking to gain the shared experience of the children and their families [38]. The qualitative data was collected by

semi-structured face-to-face interviews with the primary caregivers following the six months use of APT, and through observations from follow-up home visits, and photographs of the children when supported by the APT.

Study Procedures

Children who met the inclusion criteria had their informed consent given by their parents to participate, including consent for photographs of the children. All photographs included in this document were taken by the research team.

Each APT device was designed for the child's individual needs following an assessment based on the Oxford Assessment Tool for Complex Disability [7]. The assessment included determining the child's posture and a comfortable body position (including joint positions) required to be achieved by the APT. The customised APT construction (chair or standing frame) was based on measures taken by one of the Kenyan research assistants along with a member of the local workshop team. The construction aimed to consider the physical and social needs of the child and his/her stage of current motor development (Figures 4-7). At the time of issuing the APT to the child and family, the primary caregiver was then given both verbal and written instructions on how to use the APT with advice on any pertinent safety issues. The instruction for the care-giver was for the APT to be used at least five times each week, and to use a pictorial diary booklet (Figure 8) to record use along with any observed benefits, barriers or problems

Quantitative outcomes

The research team administering the assessments included physiotherapists, occupational therapists, a paediatrician and the Kenyan research assistants. Changes in posture, motor function and quality of life were measured by the following:

- *Family Impact of Assistive Technology Scale (FIATS - for seating) [39, 40]

- Child Engagement of Daily Life questionnaire [reference] (Figure 3) [41, 42, 43].

  .

- The DISABKIDS-Smiley measure has proven to be a reliable, valid and responsive health related QoL measure for young children [44].

*The FIATS for seated assessment was used to evaluate the standing frames because….

[Figure 3. Near here, Figure 4. Near here]

[Figure 5. Near here, Figure 6. Near here]

[Figure 7. Near here, Figure 8. Near here].

Quantitative analysis

Statistical analyses were performed using SPSS version 26. As there were less that 50 participants, normality of distribution was checked via a Shapiro-Wilk's test [45]. Normally distributed parametric data are presented as mean ± one standard deviation (SD) and non-parametric data as the median + the inter-quartile range [IQR]. A repeated measures analysis of variance test (ANOVA) and post-hoc paired samples t-tests or a Friedman test were used to determine within-group effects for parametric or no-parametric data, respectively. Statistical significance was set at $p \leq .05$

Qualitative outcomes

Device use

The primary caregivers were asked to record device usage with any positive or negative effects in a simple pictorial diary booklet (Supplementary Appendix 1).

Semi-structured interviews

Families had follow-up home visits by the research assistants during the intervention phase. Information was gained from observations and a face-to-face semi-structured interview with the primary caregivers and children using a topic guide (Supplementary Appendix 2). Notes were made at these visits. Photographs of the children using the APT seating or standing devices were taken to illustrate their use (Figures 9).

[Figure 9. Near here].

After six months device use face-to-face interviews were conducted with the primary caregivers who had completed the study. A semi-structured interview topic guide was used, and the interviews were recorded using an audio recorder. Each caregiver was asked the same questions. One researcher transcribed and translated the recordings verbatim. Another researcher analysed the data set for semantic themes with a plan to use verbatim quotes in the final analysis and consider any association with subscale changes detected by the FIATS-AS. These extracts and themes would help determine which aspects of the intervention were considered useful and had an impact on the children's and their families' lives.

Demographics from the Oxford Assessment Tool for Complex Disability provided a profile of the study participants. The qualitative data set from the follow-up home visits

and final face-to-face interviews were analysed using a deductive approach and organised to show patterns of semantic content using Braun and Clarke's [38] 6-phase guide to thematic analysis; Familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, producing the report. The aim was to report the reality and experiences of the primary caregivers, perceptions they attach to them regarding the impact that the postural support had on both their children and families. This analysis provided contextual information for our quantitative findings.

Assessment time lines

Table X., provides a summary of timeline of when each assessment and outcome measure was performed. Over the six months, there was also an ongoing provision of support by the research assistant. In the first week after commencing use of the APT, the children and families were visited or arranged for the children to be brought back (to where?) for review of….., This was repeated at regular intervals of…. to check for any skin markings/irritation or other adverse effects, to ensure the APT still fitted, and to monitor care-giver diary use including any questions, discussions, or recordings of any positive or negative effects.

At the end of the six months trial, the primary caregivers completed of the FIATS and the Child Engagement questionnaires. The qualitative analyses at this same time point, utilised information from three main sources:

i. The Oxford Assessment Tool for Complex Disability performed by two different members of the Powys research team; both were blinded to the baseline assessment data.

ii. The diary logs, and

iii. The face-to-face semi-structured interviews with the the primary caregivers conducted by the Kenyan research assistant to ascertain perceptions of the APT efficacy

Results

Of the 12 children recruited to the study, 10 with bilateral CP completed the full 6-month trial using the individualised constructed APT. Of the two that did not complete, this was due to one family moving away soon after the trial started, and the other family declined to participate for reasons unknown once they had received the APT. Participant characteristics and APT device use are summarised in Table 1. It is important to note that one child was under the minimum age criteria of 12 months, but because this was a pilot study it was felt worthwhile to include him/her . All children were cared for at home and had spasticity with full ranges of joint movements. One exception was a seven-year old boy who had a dislocated hip and restricted hip and knee movements; therefore, a reclining chair was made for him to maximize posture and comfort.

Quantitative analysis

FIATS-AS measure

Table 2. and Figure 10 summarise the changes in FIATS-AS scores at baseline and at 6-months. Observed FIAT-AS subscale values in Table 2. provide an initial illustration of changes that the children and families reported. All but one score, *Contentment* (Δ-1.3%), showed an increased value. The most prominent changes were seen in the categories of : *Doing activities* (Δ90.5%); *Safety* (Δ50.0%) and *Parent effort* (Δ45.8%). Given the small sample size and the non-parametric distribution, it was decided not to

perform multiple tests of difference on these subscale scores. Thus, the inferential analysis was only applied to the single aggregate FIATS-AS score illustrated in Figure 10, which showed an increase of 33% in the aggregate median score from 22 to 30 (Friedman test, p = .002)

[Figure 10. Near here].

[Table 2. Near here].

Child Engagement in Daily Life

Figures 12 and 13 present the descriptive and inferential data of the Child Engagement of Daily Life frequency in participation scores and perception of children's enjoyment at baseline and at 6-months.

For *Frequency in participation in Family Activities* (Figure 11), the APT increased by 38% after 6 months use (11.58 (t(9) -2.8; p= 0.021).

For *Perception of child's Enjoyment of the Activity* (Figure 12) the normally distributed data, showed a 30.6% increase after 6 months use of the APT (7.48 (t(9) -2.85; p= 0.019; 30.6%).

The *Child Engagement Participation in Self-care* was found to be not relevant in seven families who scored zero at both baseline and 6 months. This was due to the severe functional limitations based on the GMFCS IV and V levels of the children .

[Figure 11. Near here]

[Figure 12. Near here]

Qualitative analysis

Device use

Logbooks were completed by one caregiver for two weeks and another with the help of a rehabilitation worker retrospectively for four weeks only. The other eight carergivers recorded details for 8-23 weeks (mean 15wks) with chairs used for 15-60 minutes 2-3 times a day, 5-7 days a week. Standing Frames were used for 15-60 minutes, 1-3 times a day for 4-7 days a week. Two children had usage gaps greater than a week. There were no additional comments in the diaries from the caregivers regarding positive or negative effects. No adverse events were reported.

Semi-structured Interviews- Caregiver's Perceptions regarding the Impact of the Postural Support Devices

Research assistants visited four families twice during the intervention recording these visits on the follow-up home visit forms. Three home visits for a further six participants were carried out, but no notes completed due to increased work commitments. After six months device use face-to-face interviews were conducted with all ten primary caregivers who had completed the study. For this project the primary caregiver interviewees were allocated a letter from A to J. The profile of their child and the intervention are evidenced in Table 1.

[Table 1. Near here]

Thematic analysis of the ten transcripts and notes from the home-visits produced three themes where APT was of benefit: i. it had enabled improvement in the children's functional ability, ii. greater children's involvement and interaction in life situations, and iii. a reduction in the families' burden of care.

Improvement in the Children's functional ability

This theme investigates whether the stabilising postural support provided by the seating or standing device gave the children the opportunity to improve their motor skills and ability to function. Nine caregivers reported an improvement in their children's motor ability from using the device. Caregivers expressed that the devices had enabled their children to perform activities independently. Greater motor function with improved fine and gross motor skills were reported by Caregiver A (child GMFCS V)

> "Since this chair was made and she started using it, she has learnt to use her hands, she is able to control her head, and her waist and trunk are now strong in comparison with when she was not using the chair." "She can sit independently for a few minutes." "She is able to reach for toys."

Caregiver C (child GMFCS IV) concurred and stated

> "He has been able to do things differently since he started using his standing frame. He has learnt to use his hands, turn around when seated, change position, shuffle on his bottom and reach out. Before he could only sit and gaze."

Improved motor skills enabled exploration of their environment and facilitates learning and development. Caregivers observed their children to be more involved in activities of self-care such as feeding and drinking. Caregiver B (GMFCS IV) describes her child as

becoming independent at meal times “I am excited nowadays since she is feeding on her own and also holding a cup of tea and milk to drink,” a point made by Caregiver D as well “He can now hold a cup and glass and has started feeding himself.”

The data extracts suggest that the seating and standing frames provided postural support to augment motor skills for activities such as self-care and play for children of GMFCS levels IV and V.

Greater Children’s involvement and interaction in Life Situations

This theme investigates the effect of using the postural support devices upon children’s interactions and their ability to take part in every-day life. Eight primary caregivers reported that the assistive devices enabled their children to become more involved in family activities at home across all child age groups. The devices facilitated more inclusion, enabling the children to join in with their siblings in activities such as homework, mealtimes and watching television. Caregiver F asserted that “She prefers using the chair in the evenings when other children are doing their homework” and Caregiver H reported that “He prefers using the chair during lunch time when the other children come home for lunch.” Caregiver A concurred saying “It is possible to involve her in the family activities like watching television and feeding.” Many caregivers reported the utility of the devices as they could be transported and used outside, enabling their children to be more involved with outdoor activities as illustrated by figures 14 and 15. Caregiver G reported “The seat has been quite useful to my son because he’s able to stay out and enjoy the sun as he plays with some toys that I place in front of the chair.”

[Figures 14. Near here, 15. Near here]

The caregivers referred to the devices enhancing play and interaction with others in play. Caregiver B refers to the enjoyment this provides "She is also able to enjoy when she sees other children playing around her," a point also noted by Caregiver A "We can now leave her with other kids outside the house and she likes it." Caregiver G agrees reporting "He is able to participate emotionally in the games of other children since he is able to sit upright and observe and have fun as they play."

The above data extracts demonstrate that the use of postural support devices can augment interpersonal interactions and a sense of wellbeing, also providing the required postural support to allow greater involvement in activities of daily life such as indoor and outdoor play.

Reduction on the Families' Burden of care

This theme investigates whether using postural support devices impacts the household and reduces the burden of caring for children with severe disabilities. Eight caregivers reported a range of benefits with the time to undertake other duties being a recurring theme. Caregiver B reported,

> "I am able to leave them outside playing and go to the market, to the farm and other places where I need to attend to some matter." "She is also able to give me ample time to do my household chores."

While Caregiver A described a reduction in worrying about the child's safety and ability to undertake other duties and household chores,

> "For our part as parents we can now leave her and attend other duties in the farm without fear of her falling over." "She gives us time to do the household chores and sometime rest."

Caregiver D discussed a reduction in the supervision that their child required and the greater ability to attend to other household chores,

> "I can now attend to other household chores." "Being able to concentrate on my work without fear of his security and also letting him explore without too much supervision or deciding what is good for him."

In contrast, Caregiver J reported being unable to attend to other duties whilst her child was using the device as she needed to support the standing frame manually,

> "The child is able to stay in standing position with support. However, I am not able to do other activities when the child is standing because I have to support the aid."

Whilst Caregiver C reported a greater involvement from other members of the family in caring for their child, "Other family members also help in motivating him to try new things while standing, unlike before." Overall, the data extracts suggest that the use of postural support devices can reduce the burden of care for families with severely disabled children.

Discussion

The results of this study show encouraging benefits to using APT in low-resourced settings. However, there is the need for far more research to more confidently determine the efficacy of APT. The two core areas of evidence used to demonstrate these encouraging outcomes were the use of the FIATS-AS and the Child engagement

assessments. Both theses parameters were linked with the qualitative caregiver's perceptions.

FIATS-AS and Caregiver's insights

Of the nine subscales (Figure 10) the four with the highest scores were: the assistive technology device acceptance; the degree to which the children interact socially; the amount of effort required to assist the children; the ability of the children to perform activities. These higher scores indicate a greater contribution and importance of these categories to the overall impact of the device on family lives. The technology device acceptance scores indicated that the postural support devices made from APT were highly valued by all the participating families. Coupled with the positive percentage change score, this reinforces the acceptance and utility of the postural support devices by the families in this study. Records from the diary logs concur showing the seats and standing frames were consistently used throughout the study period. All families chose to keep the APT devices for their children's continuing use after completion of the study.

Benefits were indicated in the children's level of family and social interaction. The study found high median scores of 4.65; 5.15 (baseline; 6 months), along with a positive percentage change score after six months. This indicates an improvement in social interaction with device use and shows the caregivers' believed the children's ability to interact with others was highly important. This concurred with other studies [46-48]. The caregivers' interviews further support these findings, indicating the use of postural support devices had promoted their children's interaction with others.

Percentage change scores demonstrated that seven of the eight family impact subscale scores showed an increasing positive trend after 6 months device use. The greatest effects were reported in the degree to which the children performed activities and their autonomy over their actions. These findings support the evidence found from the literature that using seating or standing devices enables greater motor function and the ability to perform activities independently [11,12,17,47,49-52].

Further positive trends benefitted the caregivers. Caregivers of the children in the study were mostly mothers, and occasionally members of the extended family. Children with severe CP require more care, attention and direct supervision than children without disabilities and this caregiving increases with age. Provision of this long-term day-to-day-care often results in caregiver burden and strain [53,54]. This added caregiver burden is associated with poorer psychological and physical health for parents and other family members [39]. In this study positive effects around caregiving were indicated by a decrease in the degree the caregiver worried about their children's safety, which is consistent with the findings of both Ryan et al. [46] and Stier et al. [51] who reported safety as an important benefit of adaptive seating. Other subscales demonstrated a reduction in the amount of effort expended by the caregivers in caring for their children. To a lesser extent, the degree to which the carers needed a break from caregiving and the amount of supervision also were influenced positively by the introduction of APT devices. During their interviews, caregivers reported a reduction in the stress and family burden associated with caregiving. These findings are supported by the results from two parental surveys and one case series, where postural support devices were reported to ease caregiving [15,55,56]. This study supports findings in the literature by Ryan et al.

[46] that improved functional performance, social interaction and autonomy in children with physical disabilities, all play vital roles in mitigating caregiver burden. Postural support devices showed little or no effect on one subscale, with the degree to which the children were happy during the day showing a small decreasing trend. This finding contrasts with the child engagement in daily life caregivers' perception regarding the children's enjoyment of family activities, which showed a significant positive change. A Spearman's correlation shows no positive correlation between these measures of contentment (r_s=0.015 (p=0.967). However, the two outcome tools measure different aspects of child contentment, the FIATS-AS measuring the overall contentment during the day and the Child Engagement measuring the contentment during an activity. Research by Kurne et al. [47] in a parental survey and Ryan et al. [46] in a case series reported that a benefit of customised seating for children with severe CP was enhanced contentment during the day, again contradicting the FIATS-AS findings in this study. The lack of evidence for a positive effect on overall child contentment in the FIATS-AS may be due to the long intervention time of six months. Fuhrer et al. [57] recommend consideration of shorter-term outcomes following the introduction of assistive technology devices. There is some evidence for outcomes to be measured after six weeks, allowing families to establish a regular pattern of using a postural support device and enough time to detect the effectiveness, efficiency and satisfaction with the device [46, 58]. This shorter time frame may also mitigate the moderating influence of child development and maturation and other factors such as family, peer and community attitudes.

The significant increase in the FIATS-AS total score (figure 11) of 22.7 to 30.3 (p=0.002) showed that the use of APT seating or standing devices had a marked

positive effect on the lives of Kenyan families who have children with CP, GMFCS level IV or V. Postural support devices, in addition to having direct therapeutic benefits, play an important role in caregiving by assisting in the daily management of the children at home. The three themes derived from the caregiver interviews; improvement in the children's functional ability, greater children's involvement and interaction in life situations, a reduction in the families' burden, support these findings.

Child engagement and Caregiver's Insights

A significant increase in participation in family and recreational activities was demonstrated by the child engagement in daily life outcome measure (Figure 12). The change in frequency-in-participation mean scores of 30.5 to 42.08 ($p=0.021$) indicated that the equipment increased the children's engagement in family activities. There was a corresponding improvement and significant correlation between the activity participation subscale of the FIATS-AS findings and the frequency-in-participation scores ($r_s= 0.657$ ($p=0.039$). Most parents recounted that the APT had improved the children's motor ability and enabled more involvement in life situations and this has been supported by previous evidence globally [11,12,17,47,49-52, 59].

The self-care element of the Child Engagement in Daily Life questionnaire did not capture any change in participation; seven families scored zero at baseline and at six months follow-up. This has been previously highlighted by Palisano et al. [43] who reported that evaluating change in severely disabled children with CP (GMFCS IV and V) is a challenge, because some activities such as independent dressing, bathing and toileting will always be beyond their abilities. Therefore, the *participation in self-care*

questionnaire may have insufficient sensitivity to capture meaningful changes in this context of CP childcare and rehabilitation.

A significant increase in the perception of the children's enjoyment in participating in family and recreational activities was demonstrated by the child engagement in daily life outcome measure (Figure 13). The marked increase in children's enjoyment mean scores of 2.23 to 2.91 ($p = 0.019$) established that the APT postural support devices improved the children's level of enjoyment from participating in family activities, which contrasts to the FIATS-AS subscale findings for the children's contentment during the day, as discussed above (r_s=0.015 (p=0.967).

We conclude that APT postural support devices lead to a marked positive effect on the children's physical and psychosocial wellbeing, by enabling greater participation in family and community life. The reported themes from caregiver interviews corroborated with this overall positive effect, where APT devices benefited their children and families by enabling greater children's function, increased involvement and interaction in life situations and a perceived reduction in the family's burden of care.

Limitations of Study

Although the study showed important effects on family life due to the intervention, it had limitations. The study design is more prone to bias than other methodologies such as randomized controlled trials or cross over designs. The study attempted to minimise bias by having different assessment teams at baseline and follow up but with no control group, and a "desire to please" from participants who completed the study, a positive bias is likely. It was a pilot study with a small sample size which was not large enough

to make definitive judgements about the contributory effects of the subscales of the FIATS-AS. However, it was sufficiently powered to show positive effects resultant from the introduction of APT postural support devices, except for the participation in self-care questionnaire.

Our qualitative enquiries were less rigorous than planned. The number of home visits and ongoing therapy was less than hoped for due to capacity issues of the host organisation- which although well established and recognised for an empowering community based approach, has only one qualified therapist and few employed rehabilitation workers whose updates and remit include spiritual and social support as well as therapeutic input. One researcher completed the thematic analysis.

Conclusion

APT is a low cost and local solution to make seating and standing devices for disabled children in Kenya. The introduction of customised seating or standing devices made from APT had a meaningful positive effect on the lives of families with young children with CP of GMFCS level IV or V. The regular use of postural support devices enhanced the children's motor skills, ability to function and participate in everyday activities, reduced the burden of care for the families and promoted the children's social interaction. Primary caregiver interviews substantiated these findings. The postural support devices were both valued and highly utilised by the children and families in this study. This pilot study shows it is feasible to conduct research in a Kenyan cultural setting and a future study with a larger sample is indicated. In meeting the objectives of the Global Cooperation on Assistive Health Technology (GATE) initiative [60], further

research is required to more fully evaluate the effectiveness of postural support devices and specifically the sustainability of APT device production.

Geolocation Information

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No potential conflict of interest was reported by the authors.

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Table 1. Participant demographics and type of ATP used.

Participant	Age (years)	Gender	GMFCS level	ATP type
1	2	Female	V	Chair
2	5	Female	IV	Standing frame
3	3	Male	IV	Standing frame
4	6	Male	V	Standing frame
5	3	Male	V	Chair
6	3	Female	V	Chair
7	2	Male	V	Chair
8	7	Male	V	Chair
9	1	Male	V	Chair
10	3	Female	V	Standing frame
Median (IQR)	3 (2.25)			

Not quite sure of the relevance of the Primary Care-giver column, shouldn't this simply be the participant? In tables and figures you do need to provide a legend for any abbreviations used

Table 2. Median (IQR) subscale scores of the *Family Impact Assistive Technology Scale* (FIATS) after 6 months use of an Appropriate Paper-Based Technology postural support device (APT)

	Baseline (IQR)	6 months (IQR)	% change
Autonomy	2.5 (2.2)	3.0 (2.6)	20.0
Caregiver relief	2.3 (0.8)	2.5 (1.2)	8.7
Contentment	3.8 (1.6)	3.8 (1.0)	-1.3
Doing activities	2.1 (3.7)	4.0 (2.1)	90.5
Parent effort	2.9 (2.0)	4.3 (0.8)	45.8
Safety	2.2 (1.3)	3.3 (1.5)	50.0
Social interaction	4.6 (1.4)	5.0 (1.1)	11.0
Supervision	3.2 (1.7)	3.5 (1.2)	7.7
Device acceptance	6.0 (0.8)	6.5 (1.1)	7.5

Figure 1. Adaptive seat used in the UK.

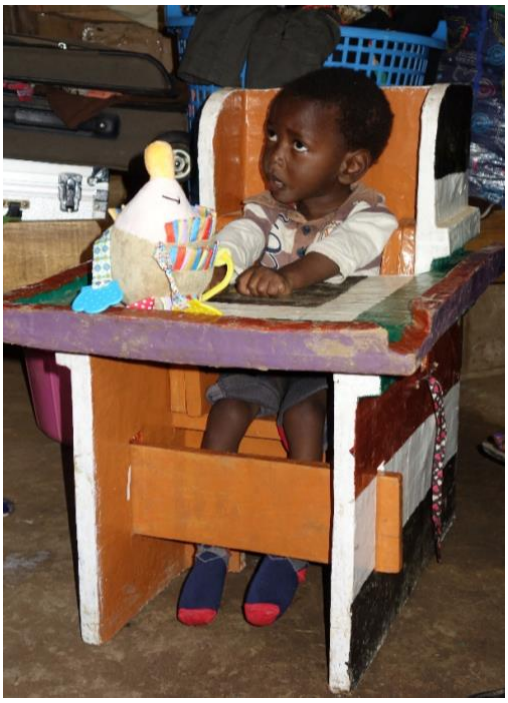


Figure 2. APT device.

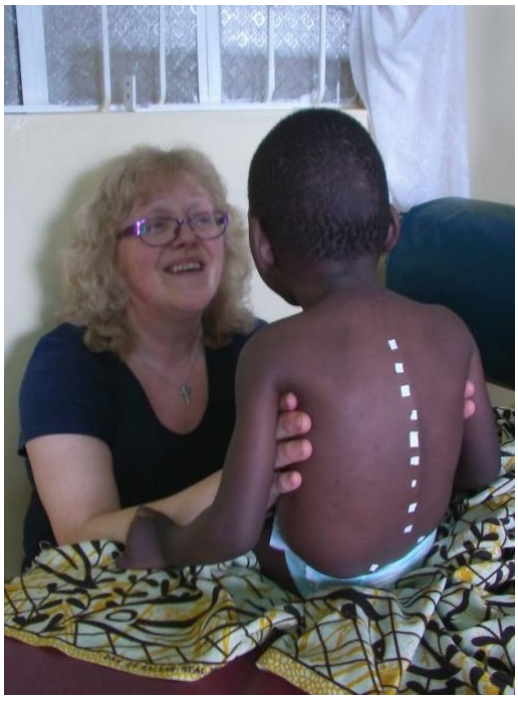


Figure 3. Therapist assessing posture.

Figure 4. Child measured for APT chair.

Figure 5. APT device being made and customised to child.

Figure 6. Adjustments for partially constructed chair agreed collaboratively.

Figure 7. APT Chair ready to take home.

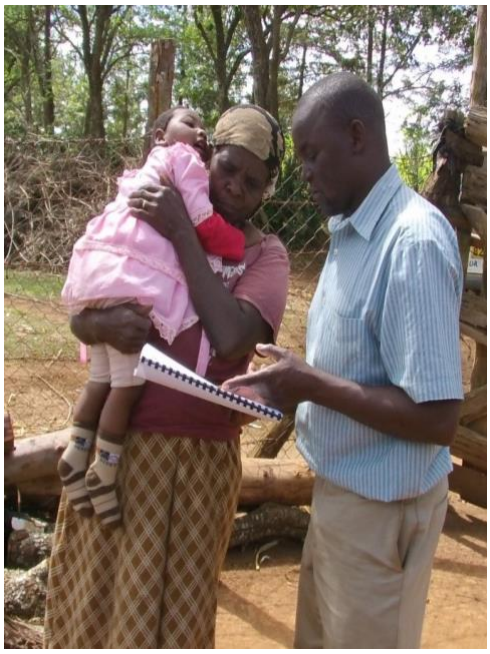


Figure 8. Explanation to the care-giver on positioning child in the APT and completing diary log

. Figure 9. At the follow-up home visit

FIATS-AS Median (IQR-error bars & % change) subscale scores at baseline and at 6-months follow-up after APT postural support device use.

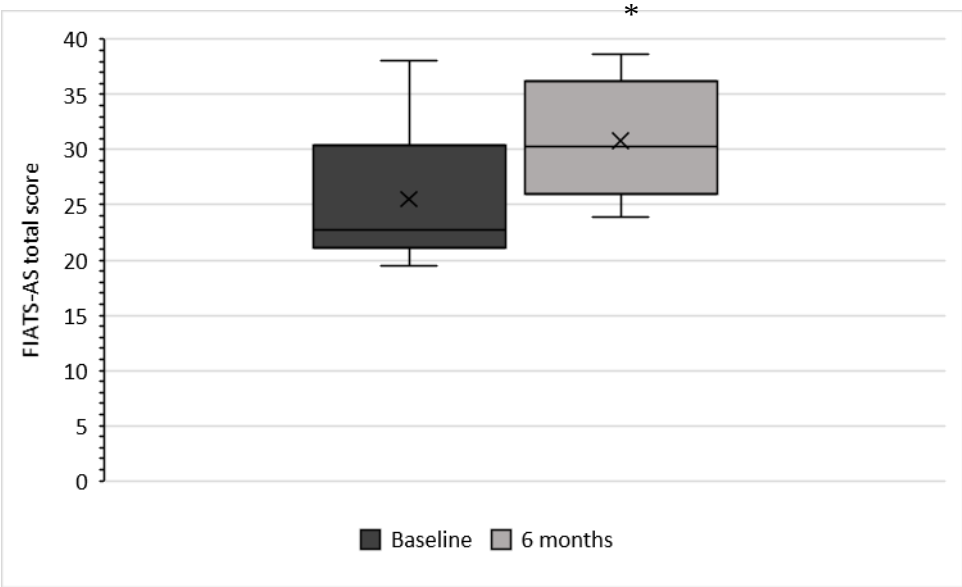


Figure 10. Median aggregate FIATS-AS score (after 6 months use of APT (error bars = IQR). (The score does not include Device Acceptance domain WHY?) *p=0.002

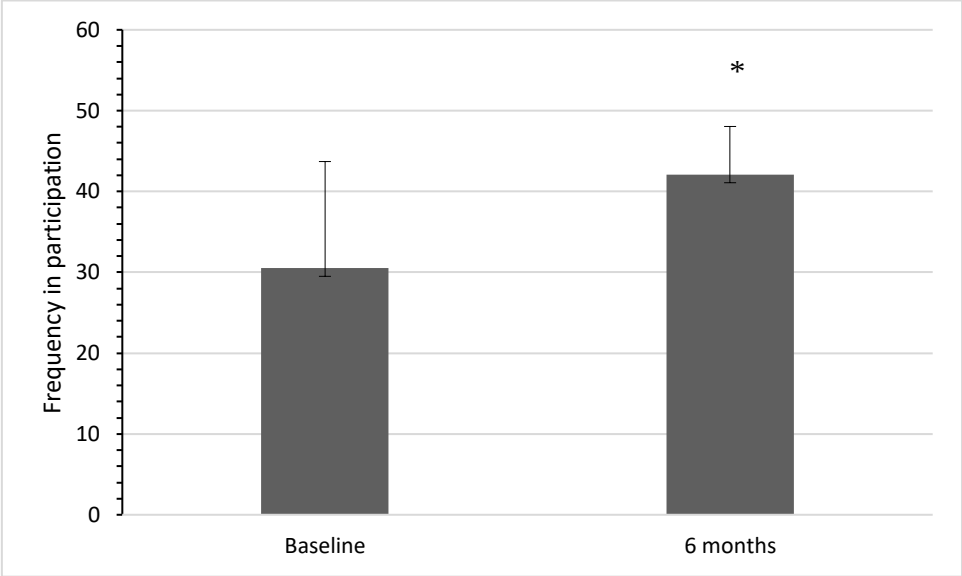
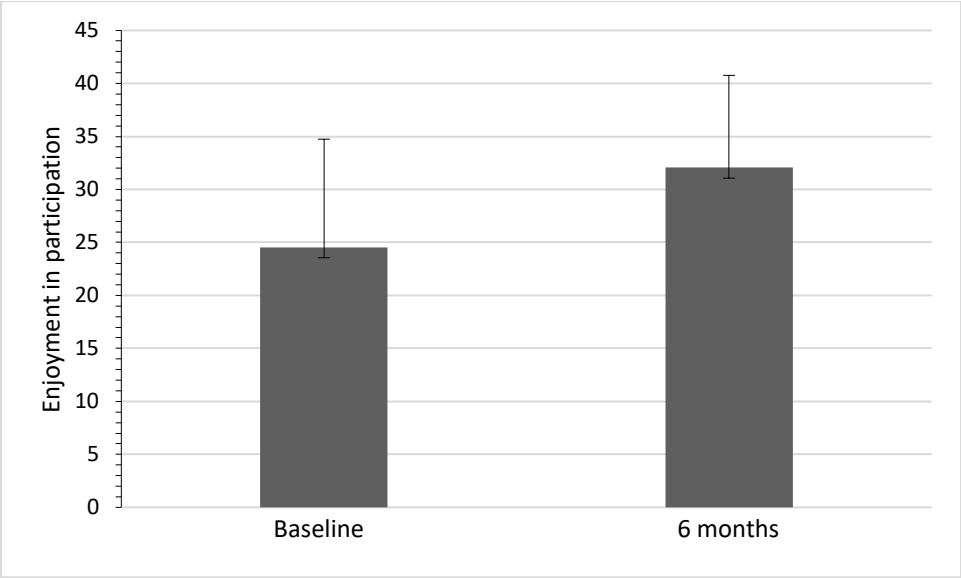


Figure 12. Mean (SD) Child Engagement Frequency (what are the units of frequcny, which needs to be on the y axis?) in participation after 6 months use of APT. *p=0.021



*p=0.019

Figure13. Mean (Child Engagement Enjoyment in participation Mean score at baseline and at 6 months follow-up after APT postural support device use.

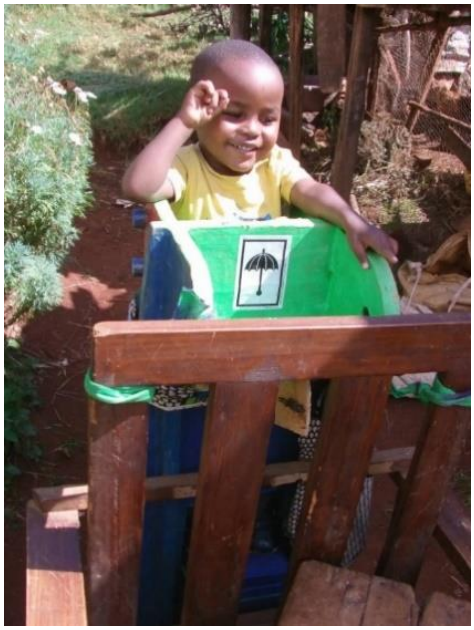


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Figure 11. FIATS-AS Median (IQR-error bars) overall score (doesn't include Device Acceptance domain) at baseline and at 6 months follow-up after APT postural support device use.

Figure 12. Child Engagement Frequency in participation Mean (SD-error bars) score at baseline and at 6 months follow-up after APT postural support device use.

Figure13. Child Engagement Enjoyment in participation Mean (SD-error bars) score at baseline and at 6 months follow-up after APT postural support device use.

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